Dementia Curriculum for Health Care Professionals

Module 10: References

Effective Care Transitions to and from Acute Care Hospitals







Module 10 References

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Module 10 Resources

Government-funded resources and services:

Administration for Community Living (ACL): https://www.acl.gov/programs/long-term-care-planning.

This site provides tools, resources, and links with a range of information about long-term care. It includes the LTC PathFinder to provide individuals with information most relevant and useful to them.

Alzheimer's Disease Centers (ADCs): (Link currently disrupted but can be found by a web search for ADCs). Patients with complicated management or uncertain diagnoses may be referred to locations in major medical institutions in many states. If patients are enrolled in the ADC, they may be able to receive:

- Help with diagnosis and medical management (Costs may vary—ADCs may accept Medicare, Medicaid, and private insurance)
- Information about the disease, services, and resources
- Opportunities to participate in clinical trials, studies, and patient registries
- Opportunities to participate in support groups and other special programs for their families

Alzheimer's Disease Education and Referral (ADEAR) Center: https://www.nia.nih.gov/alzheimers/. Patients and their care partners can peruse the website of this National Institute on Aging center for:

- Free publications about Alzheimer's disease and related disorders, symptoms, diagnosis, risk factors, treatment, caregiving tips, home safety tips, and research
- Culturally appropriate and Spanish-language resources (See Module 3 for additional materials)

Eldercare Locator: (800) 677-1116 (toll-free); www.eldercare.gov. Sponsored by the U.S. Administration for Community Living, the Eldercare Locator can help to identify community services for older adults and their families.

National Association of Area Agencies on Aging (n4a): http://www.n4a.org/adrcs. Area Agency on Aging (AAA) local offices and Aging and Disability Resource Centers (ADRCs) (whose available services vary by state and locality) advise persons living with dementia and their care partners about services such as assistance with planning, transportation, in-home care services, case management, provision of or payment for home modifications, and use of a tablet care coordination platform. Many AAAs around the country have a formal care transitions program (http://www.n4a.org/caretransitions).

National Clearinghouse for Long-Term Care Information:

http://www.healthinaging.org/resources/resource:national-clearinghouse-for-long-term-care-information/. Developed by the U.S. Department of Health and Human Services, this site provides information and resources to help individuals and their families plan

for future long-term care needs. It helps individuals understand what long-term care is, how and where to get information and services (now or in the future), and how to pay for services.

National Family Caregiver Support Program (NFCSP): (the link is currently disrupted but the information below can be found by doing a web search).

This grant program, funded by the AoA's Administration for Community Living (ACL), provides care partners with the following:

- Information about available services
- Assistance in gaining access to these services
- Individual counseling, organization of support groups, and training
- Respite care

Supportive Services and Senior Centers Program:

AoA/ACL's Home and Community-Based Supportive Services (HCBS), through grants to states and territories, provides services in the following areas:

- Transportation
- In-home services, such as personal care, chore, and homemaker assistance
- · Community services, such as mental health services and adult day care
- Multipurpose senior centers that coordinate and integrate services for older adults, such as congregate meals, community education, health screening, exercise/health promotion programs, and transportation
- Congregate nutrition services
- Home-delivered nutrition services

State Health Insurance Assistance Programs (SHIPs): https://www.shiptacenter.org/about-us/about-ships.

Medicare beneficiaries, or individuals who are potentially Medicare-eligible and their care partners who need help in clarifying their insurance coverage, can contact SHIPs. These programs operate in all 50 states, the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands. They provide the following:

- Free, in-depth, one-on-one counseling on Medicare and Medicare-related health insurance plans
- Free assistance in obtaining coverage under Medicare and Medicare-related health insurance plans
- Referrals, as appropriate, to other agencies such as the Social Security Administration and local Medicaid offices

Nongovernmental organizations and resources:

The Alzheimer's Association, national and local chapters: http://www.alz.org/
we can help local chapters wch.asp#Core programs and services.

- <u>s.</u> Persons living with dementia and their care partners can find resources and information on several services through this site, including the following:
 - Educational workshops
 - Support groups (in person and online):
 http://www.alz.org/apps/we_can_help/support_groups.asp
 - Assistance finding clinical trials
 - Information and advice through a professionally staffed 24/7 helpline
 - Safety devices that provide location management for persons with Alzheimer's disease who wander (charges involved)

Alzheimer's Foundation of America (AFA): http://www.alzfdn.org/. The AFA and its member organizations offer persons living with dementia and their care partners many resources (which vary by organization):

- Information, counseling by licensed social workers, and referrals to community resources through a helpline; also available via email, Skype, and live chat
- Identification of programs that help locate persons with Alzheimer's disease who wander
- Scholarships for respite services
- Educational workshops

Association for Frontotemporal Degeneration: Persons with frontotemporal degeneration (FTD) and their care partners can contact this association for several types of assistance:

- Small respite grants and grants to travel to an FTD education conference: http://www.theaftd.org/life-with-ftd/resources/travel-grants
- Information on local and telephone support groups can also be found on their website but the link can only be accessed from their home page at https://www.theaftd.org/what-is-ftd/disease-overview/
- Helpline for finding information, resources, and support: (866) 507-7222

Family Caregiver Alliance (FCA): https://caregiver.org/support-groups (and (800) 445-8106 (toll-free). The FCA offers several types of support groups, both online and inperson.

Frontotemporal Dementia (FTD) Support Forum: http://www.ftdsupportforum.com/

Lewy Body Dementia Association (LBDA): Persons with Lewy Body Dementia and their care partners can contact the LBDA for the following:

- In-person support groups https://www.lbda.org/go/local-lbd-support-groups
 Online support groups http://www.lbda.org/content/virtual-groups
- The LBD Caregiver Link (800) 539-9767. Features "Lewy Buddies"—
 experienced care partners who can provide information on LBD, offer emotional
 support, and help identify resources about diagnosis and care

National Long-Term Care (LTC) Ombudsman Resource Center: http://ltcombudsman.org/. This citizen group advocates for rights of residents in long-term care facilities, educates consumers and providers, helps resolve residents' complaints, and provides information.

National Stroke Association: www.stroke.org. This site features several resources for patients with vascular dementia.

National Transitions of Care Coalition (NTOCC): http://www.ntocc.org/Home.aspx. This coalition provides tools and resources to patients, care partners, health care professionals, and policymakers who seek to address challenges in meeting the needs of patients transitioning between care settings.

Online publications:

Going to the Hospital (the link to this page is currently disrupted but can be accessed through a web search for Going to the Hospital: Tips for Dementia Caregivers

Transitions of Care Checklist:

http://www.ntocc.org/Portals/0/PDF/Resources/TOC_Checklist.pdf

What the Discharge Planner Needs to Know in Order to Effect a Safe and Efficient Transition. New York State Department of Health.

https://www.health.ny.gov/professionals/patients/discharge_planning/discharge_checklist.htm

Your Discharge Planning Checklist: https://www.medicare.gov/pubs/pdf/11376-discharge-planning-checklist.pdf